

Health Record Banking Alliance

A Health Record Bank (HRB) is an organization that serves as the trusted custodian of up-to-date copies of any electronic healthcare information selected by a consumer for inclusion in his/her account. All access to the information in the account is controlled by the account-holder (the consumer), who makes the information available to health care providers whenever necessary. Each consumer may also access his/her own record as needed. Health Record Banks are required to follow stringent privacy and confidentiality practices to protect the information (either via open and transparent community oversight or legally-mandated government regulation). When seeking care, the account-holder can identify his/her Health Record Bank and give permission for the caregiver to access his/her records (either all or part) through a secure Internet portal. When the care episode is completed, the caregiver, with consumer consent, can then transmit any new health information that was generated to the consumer's HRB where it will be added to the account-holder's lifetime health record information (through the Health Record Bank's "deposit window").

When public health authorities or medical researchers need to search electronic health care information, they can submit queries to the relevant Health Record Bank(s). Each Bank will process the query using information from all account-holders that have agreed to allow that particular use of their data. If fees are charged, the revenue can be shared with account-holders as an incentive to allow such use. Confidentiality can be enforced by limiting the response to the query to those records that meet whatever criteria were submitted and by sending a message to each account-holder matching the query conditions. This will, for example, allow notification of account-holders of their eligibility for a clinical trial.

Thus, health record banking provides important functionality needed for the national health information infrastructure (NHII), and HRBs will act as "co-equal nodes" within the NHII. With each person's lifetime health record stored in one place (and carefully protected), there is no need for Health Record Banks to communicate with each other -- except when there is an occasional need to transfer an account from one Bank to another.

The Health Record Banking Alliance (HRBATM) is a non-profit organization formed to assist stakeholders in the promotion of community repositories of electronic health records (HRBs). The HRBA includes participants from all of the major stakeholder groups in healthcare. As part of its initial activities, HRBA has developed the following principles:

Consumer Ownership and Control of Health Records

- 1. Health record banks protect the individual consumer's right to health information privacy and confidentiality by acting as trusted legal custodians of consumers' health records.
- 2. Health record banks are repositories for trustworthy copies of health information selected or submitted by the consumer from various sources.
- 3. Health information in a health record bank is owned by the consumer and is not an asset of the health record bank.
- 4. Consumers may authorize someone else to manage their health record bank account.
- 5. Health record banks provide consumers and others they authorize with immediate electronic access to their health information.
- 6. Consumers control all disclosures of their health information by a health record bank unless otherwise required by law.
- 7. With consumer consent based on advance disclosure appropriate to the circumstances, health record banks enable secondary use of health information, such as for public health and research purposes.

Operation of Health Record Banks

- 8. Health record banks are governed in an open, accountable, and transparent manner.
- 9. All access and updates to information in health record banks are recorded as they occur in an appropriately detailed audit trail database, and each health record bank shall maintain those unaltered audit records at least during the time that a consumer's health record is kept at the bank and make those audit records immediately accessible to consumers.
- 10. Health record banks have established processes for correcting errors by updating, amending, and sequestering data, including mechanisms for notification of parties who have received such data.
- 11. Health record banks promptly disclose breaches of privacy, confidentiality, or security to consumers.

Operation of the Health Record Banking Alliance

12. The Health Record Banking Alliance seeks to maintain neutrality among vendors that agree to adhere to the above principles.

Definitions used in the statement of principles.

Derived from a letter from the National Committee on Vital and Health Statistics to Secretary of HHS sent to Michael Leavitt, 6/22/06. Available at http://www.ncvhs.hhs.gov/060622lt.htm, accessed 5/9/07.

<u>Health information privacy</u> refers to an individual's right to control the acquisition, use, or disclosure of his or her identifiable health data.

<u>Confidentiality</u> refers to the obligations of those who receive information to respect the privacy interests of those to whom the data relate.

<u>Security</u> refers to the physical, technological, or administrative safeguards or tools used to protect identifiable health data from unwarranted access or disclosure.

Submitted to AHIC by: William A. Yasnoff, MD, PhD Chairman and CEO Health Record Banking Alliance P.O. Box 17436 Arlington, VA 22216-1743

phone/fax: 703/527-5678

email: william.yasnoff@healthbanking.org